

# ERROR CORRECTION FORM

Sequence Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

CIBMTR Recipient ID:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Initials:

--

Today's Date:

		2	0		
Month	Day	Year			

Infusion Date:

		2	0		
Month	Day	Year			

CIBMTR Center Number:

--	--	--	--	--	--	--	--



## Leukodystrophies Post-HSCT Data

Registry Use Only

Sequence Number:

--

Date Received:

--

CIBMTR Center Number:

--	--	--	--	--	--	--	--

CIBMTR Recipient ID:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Today's Date:

		2	0		
Month	Day	Year			

Date of HSCT for which this form is being completed:

Month	Day	Year			

HSCT type:  autologous  allogeneic, unrelated  allogeneic, related  syngeneic (identical twin)

Product type:  marrow  PBSC  cord blood  other product, specify: \_\_\_\_\_

Visit:  100 day  6 month  1 year  2 years  > 2 years, specify:

**To be completed in conjunction with a Form 2100 – 100 Days Post-HSCT Data, Form 2200 – Six Months to Two Years Post-HSCT Data, or Form 2300 – Yearly Follow-Up for Greater Than Two Years Post-HSCT Data. Information reported here should reflect the date of last contact as reported in the post-HSCT data collection form, or immediately prior to death.**

1. For which type of leukodystrophy was the transplant performed?

1  globoid cell leukodystrophy →

2. Specify the leukocyte galactocerebrosidase enzyme activity since the date of the last report: 



 . 



 1  nmol/hr/mg protein 2  pmol/hr/mg protein

3. Date tested: 



 / 



 / 







 date unknown

2  metachromatic leukodystrophy →

4. Specify the leukocyte arylsulfatase A enzyme activity since the date of the last report: 



 . 



 1  nmol/hr/mg protein 2  pmol/hr/mg protein

5. Date tested: 



 / 



 / 







 date unknown

3  adrenoleukodystrophy

**For 100-day follow-up reports, only questions 1–6 are required. Please sign below and submit only page 1 of this form. For all visits beyond 100 days post-HSCT, continue with question 7.**

6. Signed: \_\_\_\_\_  
Person completing form

Please print name: \_\_\_\_\_

Phone number: ( \_\_\_\_\_ ) \_\_\_\_\_

Fax number: ( \_\_\_\_\_ ) \_\_\_\_\_

E-mail address: \_\_\_\_\_

# ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Initials:

Today's Date:

  
Month Day

20

Year

Infusion Date:

  
Month Day

20

Year

CIBMTR Center Number:

CIBMTR Center Number:

CIBMTR Recipient ID:

## Clinical Status Post-HSCT

7. Is there a history of post-HSCT seizures attributed to the underlying disease since the date of the last report?

- 1  yes  
2  no  
3  unknown

8. Was cerebrospinal fluid (CSF) testing performed since the date of the last report?

- 1  yes  
2  no  
3  unknown

Specify the results of most recent tests:

9. Date of most recent test:

- 1  known  
2  not known

  
Month Day

20

Year

10. Opening pressure:

- 1  known  
2  not known

cm H<sub>2</sub>O

11. Closing pressure:

- 1  known  
2  not known

cm H<sub>2</sub>O

12. Total protein:

- 1  known  
2  not known

1  mg/dL

2  g/L

13. Was Magnetic Resonance Imaging (MRI) performed since the date of the last report?

- 1  yes  
2  no  
3  unknown

14. Date of most recent MRI:

- 1  known  
2  not known

  
Month Day

20

Year

15. Specify MRI results:

- 1  normal  
2  abnormal

16. Is a copy of the MRI report attached?

- 1  yes  
2  no

17. Was Magnetic Resonance Spectroscopy performed since the date of the last report?

- 1  yes  
2  no  
3  unknown

18. Date of most recent test:

- 1  known  
2  not known

  
Month Day

20

Year

19. Specify test results:

- 1  normal  
2  abnormal

20. Is a copy of the report attached?

- 1  yes  
2  no



# ERROR CORRECTION FORM

Sequence Number:

CIBMTR Recipient ID:

Initials:

Today's Date:

  
Month Day  
  
2 0  
Year

Infusion Date:

  
Month Day  
  
2 0  
Year

CIBMTR Center Number:

CIBMTR Center Number:

CIBMTR Recipient ID:

39. Was the recipient's visual acuity tested since the date of the last report?

- 1  yes  
2  no  
3  unknown

40. Is the recipient blind?

- 1  yes  
2  no

41. Date of most recent visual acuity test:

- 1  known  
2  not known
- 
- 
- 
- Month Day
- 
- 
- 
- 
- 
- 
- 2 0
- 
- Year

42. Visual acuity of right eye (OD): (*uncorrected vision*)

- 1  known  
2  not known
- 
- 
- 
- /
- 
- 
- 
- 

43. Visual acuity of left eye (OS): (*uncorrected vision*)

- 1  known  
2  not known
- 
- 
- 
- /
- 
- 
- 
- 

44. Visual acuity of both eyes (OU): (*uncorrected vision*)

- 1  known  
2  not known
- 
- 
- 
- /
- 
- 
- 
- 

45. Did the recipient undergo an ophthalmologic exam under anesthesia since the date of the last report?

- 1  yes  
2  no  
3  unknown

46. Date of most recent exam:

- 1  known  
2  not known
- 
- 
- 
- Month Day
- 
- 
- 
- 
- 
- 
- 2 0
- 
- Year

47. Specify results:

- 1  normal  
2  abnormal / impaired

48. Is a copy of the report attached?

- 1  yes  
2  no

49. Was an audiologic evaluation (auditory brain stem or conditioned response) performed since the date of the last report?

- 1  yes  
2  no  
3  unknown

50. Date of most recent evaluation:

- 1  known  
2  not known
- 
- 
- 
- Month Day
- 
- 
- 
- 
- 
- 
- 2 0
- 
- Year

Specify tympanometry results:

51. 1  normal 2  retracted 3  flat Right ear  
52. 1  normal 2  retracted 3  flat Left ear

# ERROR CORRECTION FORM

Sequence Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

CIBMTR Recipient ID:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Initials:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

Today's Date:

Month	Day	Year		Year		Year		Year		Year		Year		Year		Year		Year	

Infusion Date:

Month	Day	Year		Year		Year		Year		Year		Year		Year		Year		Year	

CIBMTR Center Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

CIBMTR Center Number:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

CIBMTR Recipient ID:

--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--	--

53. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 500 hertz (HZ) since the date of the last report?

- 1  yes  
2  no  
3  unknown

54. Date of most recent evaluation:

- 1  known  
2  not known
- |       |     |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |
|-------|-----|------|--|------|--|------|--|------|--|------|--|------|--|------|--|------|--|------|--|
|       |     |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |
| Month | Day | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  |

Specify tympanometry results: (See Degree of Hearing Loss chart below for scale ranges.)

55. 1  normal / mild 2  moderate / moderately severe 3  severe / profound Right ear  
56. 1  normal / mild 2  moderate / moderately severe 3  severe / profound Left ear

57. Was the hearing loss (HL) in decibels (dB) assessed at the speech threshold for 2000 hertz (HZ) since the last report?

- 1  yes  
2  no  
3  unknown

58. Date of most recent evaluation:

- 1  known  
2  not known
- |       |     |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |
|-------|-----|------|--|------|--|------|--|------|--|------|--|------|--|------|--|------|--|------|--|
|       |     |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |      |  |
| Month | Day | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  | Year |  |

Specify tympanometry results: (See Degree of Hearing Loss chart below for scale ranges.)

59. 1  normal / mild 2  moderate / moderately severe 3  severe / profound Right ear  
60. 1  normal / mild 2  moderate / moderately severe 3  severe / profound Left ear

### Degree of Hearing Loss: Pure Tones and Speech Testing

Normal:	0-20 dB HL	Moderate:	45-55 dB HL	Severe:	75-90 dB HL
Mild:	25-40 dB HL	Moderately Severe:	60-70 dB HL	Profound:	> 90 dB HL

61. Has there been a change in the recipient's neurologic status since the date of the last report?

(Report clinical status, not neuropsychological status.)

- 1  yes  
2  stable / unchanged  
3  unknown

62. Specify current neurologic status compared to previous report:

- 1  improved  
2  worsened

63. Is a copy of the physical exam or neurologic exam attached?

- 1  yes  
2  no